

**For the Local Safeguarding Adults Board for Bedford Borough
Council and Central Bedfordshire Council**

Safeguarding Adults Review

Mr B

Lead Reviewers:

Sheila Fish and Fran Pearson

4th August 2020_Final Version

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1 Introduction

1.1 SUCCINCT SUMMARY OF THE CASE

1.1.1 This case focuses on the work of agencies over a six-month period, attempting to help Mr B after he developed an infection in his leg. Mr. B was in his early 80s and had previously managed his life in his own way, without any request or identified need for support, beyond universal services from his GP particularly to support his diabetes. A lifetime of hoarding however made treating the infections that had developed on his legs challenging because there was hardly any space left in his house, and he was sleeping on a dining room chair in a small 'cave' amid accumulated possessions. In addition, he was reluctant to take medication. There were two hospital admissions triggered by his being found in a confused state, leading to safeguarding referrals due to the fire risk and concerns about self-neglect and support from the Reablement Team, commissioned by the hospital social work service. It was a highly stressful time for his wife and adult-children and children-in-laws who were very alive to the risks to Mr. B yet were faced with a lack of professional intervention. Specific mental capacity assessments concluded that Mr. B had capacity to refuse help and understand the risks related to his home situation.

1.2 WHY THIS CASE WAS CHOSEN TO BE REVIEWED

- 1.2.1 In July 2018 the Reablement Team responded to Mr B's own report that he was having hallucinations by seeking advice from NHS 111 and contacting the GP practice for further assessment, which was the advice given. The cause, extent and impact of the hallucinations were never fully established. Some six weeks later, one of Mr B's regular carers was concerned that he had not been at home since the previous day. The carers knew his patterns and for him to be out for some hours was not at all unusual, but this was, and she reported him missing to Bedfordshire Police. The same day, 2nd September, a member of the public reported seeing a man walk into the river Ouse near the centre of Bedford and very sadly the recovered body was that of Mr B, whose home was nearby.
- 1.2.2 Bedford Borough Council Adult Services referred Mr B's case to the Local Safeguarding Adults Board, for Bedford Borough and Central Bedfordshire and a decision was made on 23rd October 2018 to carry out a Safeguarding Adults Review. This is in line with section 44 of the Care Act 2014. Mr B was an adult at risk as defined by the Care Act.
- 1.2.3 Section 44 of The Care Act 2014 requires Safeguarding Adults Boards to undertake a Safeguarding Adult Review as follows¹:

¹ <http://www.legislation.gov.uk/ukpga/2014/23/section/44/enacted>

(1) “A SAB must arrange for there to be a review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if—

- (a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and
- (b) condition 1 or 2 is met.

(2) Condition 1 is met if—

- (a) the adult has died, and
- (b) the SAB knows or suspects that the death resulted from abuse or neglect (whether or not it knew about or suspected the abuse or neglect before the adult died).

1.2.4 In Mr B’s case, Condition 1 was met.

1.3 METHODOLOGY, PERIOD UNDER REVIEW AND THE RESEARCH QUESTIONS

1.3.1 The purpose of a SAR is:

- To promote effective learning and improvement to services and how they work together;
- To learn lessons about how the local safeguarding system works that will help to reduce the likelihood of future harm;
- To understand what happened and why;

1.3.2 The SAB decided to use a Learning Together review approach (Fish, Munro & Bairstow 2010). This approach supports learning and improvement in safeguarding adults. The aim of this is to support involved staff, managers and strategic staff to use systems thinking to develop an understand of the practice and to promote a culture of learning between involved partners.

1.3.3 Learning Together provides the analytic tools to support both rigour and transparency to the analysis of practice in the case and identification of systems learning. This creates a two stage process:

- We broke the time line down into Key Practice episodes. The quality of practice in each episode was analysed, and contributory factors identified.
- From the case analysis we drew out underlying systemic issues that help or hinder good practice more widely. The Learning Together findings structure requires the provision of evidence about the generalisability of issues that were identified in the case.

1.3.4 The approach has involved two distinct groups of participants:

Case Group - Practitioners with direct case involvement and their line managers; who are central to the learning event

Review Team - Senior managers with no case involvement who have a role in helping develop system learnings and supporting the case groups representatives if needed.

They play an important role in bringing wider intelligence to ascertain which issues are case specific only, and which represent wider trends locally.

1.3.5 We also sought to engage with family members to talk through the analysis, answer any queries and gain their perspectives.

TIME PERIOD

1.3.6 It was agreed that the review would focus on the period between 1st April 2018 and 15th September 2018, purposely taking the timeline beyond the date of Mr B's death in order to include the way that organisations responded to his family in the immediate aftermath of this very sad event.

RESEARCH QUESTIONS

1.3.7 The use of research questions in a 'Learning Together' systems review is equivalent to Terms of Reference. The research questions identify the key lines of enquiry that the SAB want the review to pursue and are framed in such a way that make them applicable to casework more generally, as is the nature of systems Findings. The research questions provide a systemic focus for the review, seeking generalizable learning from the single case. The research questions agreed for this SAR were:

- 1.3.8 What can we learn from Mr B's case about factors in Bedford's adult safeguarding system that help or hinder in
- a) Picking up changes and/ or deterioration, and the coordination that enables change to be identified and understood
 - b) Assessing capacity and working with 'unwise decisions'
 - c) Establishing who family carers are and mutual expectations about their roles

1.4 INVOLVEMENT AND PERSPECTIVES OF THE FAMILY

1.4.1 Mr B's wife and daughter met with one of the reviewers at the very start of the process and offered to send in a 'family chronology'. They were supported by an advocate and the reviewers would like to begin by thanking Mr B's family who by the very act of going over events again, were doing something that is painful and much appreciated. As well as having contributed to a Serious Incident Review by the mental health trust, they were also in the midst of preparing for an inquest which meant this review was not the only difficult process under way for them. Their starting point for the generous amount of time they gave was that they want to prevent a repetition for other families of their experience, and that the system will learn. We hope that this report supports that goal.

1.4.2 Mr B's family members talked about the decades of difficulties of having a former husband and father with Mr B's temperament, world view and habits. This resulted in family separation and estrangement although he was still in regular contact with his former wife, going for a meal at her home once a week. Reflecting on the period under review however, the family members were clear that what started happening to Mr B in late March and early April 2018 was a new and distinct deterioration in his ability to cope and that something significant changed. They attempted to convey this to professionals, but are not confident it

was heard or understood.

- 1.4.3 The family chronology reflects on the most significant interactions they had with professionals, and is focused on the first of his two hospital admissions for delirium and cellulitis and the question of what mental capacity meant in the context of Mr B.

1.5 REVIEWING EXPERTISE AND INDEPENDENCE

- 1.5.1 This Safeguarding Adults Review was carried out by Dr Sheila Fish and Ms Fran Pearson. Both are independent of all services in Bedford, although Fran Pearson is independent chair of Luton Safeguarding Adults Board so is familiar with some of the organisations involved in this review. Dr Sheila Fish helped develop the Learning Together methodology used here and between them, the two reviewers have carried out over thirty safeguarding reviews, on the cases of both adults and children.

1.6 STRUCTURE OF THE REPORT

- 1.6.1 First, an overview is provided of what happened in this case. This clarifies the view of the review team about how timely and effective the help that was given to Mr B and his family was, including where practice was below or above expected standards and explaining why.
- 1.6.2 A transition section reiterates the ways in which features of this particular case are common to other work that professionals conduct with other families and therefore provides useful organisational learning to underpin improvement.
- 1.6.3 The systems findings that have emerged from the SAR are then explored. Each finding also lays out the evidence identified by the Review Team that indicates that these are not one-off issues. Evidence is provided to show how each finding creates risks to other adults in future cases, because they undermine the reliability with which professionals can do their jobs.

2 Appraisal of professional practice in this case

2.1 2.1 BRIEF TIMELINE OF THE PERIOD UNDER REVIEW

Date	What happened	Source (can be removed final version)
27 th March 2018	Mr B attends the GP surgery following a phone consultation the previous day. He is diagnosed with cellulitis to both legs and prescribed an emollient and antibiotics.	GP chronology
4 th April 2018	Mr B phoned his former wife early in the morning. She was worried that he sounded confused and tried to phone the doctors on his behalf. At midday, his daughter phoned the doctor's surgery	Family chronology
11 th April 2018	A GP sees Mr B, along with family members. The situation with his legs is not improving and he has not taken the antibiotics as he wants to gain a better understanding of side effects	GP chronology
13 th April 2018	<u>First Safeguarding Referral</u> Mr B is brought into A&E by paramedics. He is confused and not coping. They make a safeguarding referral to the local authority social work team on the basis of concerns about the condition of his house, feeling he is unsafe to return home due to the level of hoarding	GP chronology; Ambulance Trust chronology; Hospital Trust Chronology
17 th April 2018	Mr B is assessed on the ward he was admitted to by an Occupational Therapist. He declines hospital social work team involvement. He is 'deemed to have capacity and insight into home circumstances'	Hospital Trust Chronology

23 rd April	Mr B has been medically fit for discharge since 18 th April. He is assessed by a member of the hospital social work team	Hospital Trust Chronology
25 th April	Mr B is reassessed by a member of the hospital social work team and they also talk on the phone to his daughter, who gives a family perspective.	Hospital Trust Chronology
26 th April	Mr B was assessed by the Psychiatric Liaison service (PLS) but no need for any intervention was identified and his case was closed. Mr B continued to decline help and was discharged home	ELFT Serious Incident Report
13 th May 2018	A passing member of the public found Mr B slumped on a bench. He was admitted to hospital again with confusion	Ambulance Trust chronology
13 th May 2018	<u>Second safeguarding referral</u> This was based on information the ambulance crew had received from Mr B's wife and their observation of signs of self-neglect with Mr B. The Safeguarding referral was sent to Bedford Borough Social Care with a copy to the GP, and to the mental health trust, where after a delay in triaging it, the referral was not sent on as planned to the Older People's team and therefore not followed up	Ambulance Trust chronology
15 th May 2018	An Occupational Therapist notes Mr B's daughter's concerns. Mr B himself says he would like his family involved in discharge planning and is more agreeable to proposed help at home	Hospital Trust chronology
21 st May 2018	While Mr B is still in hospital, Environmental Health officer, having been contacted by Mr B's family, initiates a referral to, and joint visit with, the Fire Service to	

	Mr B's house. A Fire Risk Assessment including clutter rating, is completed	
24 th May 2018	Mr B is discharged and because social work staff have managed to get Mr B's agreement to the reablement service, that service starts the following day	
14 th July 2018	<p><u>Third safeguarding referral</u></p> <p>An ambulance was called after a friend of Mr B's contacted NHS 111 concerned that Mr B was hallucinating. The referral was due to 'the state of the property'. The back door was 'blocked by objects' and aside from a space in an upstairs bedroom for a chair which Mr B appeared to sleep on, the rest of the upstairs 'is inaccessible'. [although] fire alarm has been recently fitted. Gas boiler has been disconnected and fridge does not work. Most lights in the house are not working. Sink has moss growing on it. Clutter scale of 8'</p>	Ambulance Trust chronology
16 th July 2018	Although the ambulance crew had not found Mr B to be hallucinating on 14 th , one of the reablement team contacted the GP asking for an appointment for Mr B, as they were concerned about a urinary tract infection and confusion. A paramedic employed by the GP to assess acute illness was sent and got access on the third day of trying, having sought guidance from the GPs after each unsuccessful attempt to see Mr B	GP chronology
13 th August 2018	Mr B was discussed at the multidisciplinary team meeting at the GP practice but the outcomes are unclear	GP chronology

16 th August 2018	In a reassessment over the phone of Mr B's care by the local authority worker allocated to him, Mr B made it clear he would not be prepared to pay for his care which his financial situation would make necessary. He talked about some of his other problems such as that of his sight but declined other help. This resulted in a decision later in the month to waive the charges for his care in recognition of the risk of him refusing it	Bedford Borough Council Chronology
2 nd September 2018	One of Mr B's reablement carers reported him missing to Bedfordshire police as he had not been seen the entire day before and was still not home	Beds Police record
2 nd September 2018	Very sadly, Mr B's body is found in the river near his home	

2.2 IN WHAT WAYS DOES THIS CASE PROVIDE A USEFUL WINDOW ON OUR SYSTEM?

- 2.2.1 Mr. B is of course unique but, for the purposes of learning, in many ways he is not dissimilar to other individuals who have had a lifetime of hoarding, that they do not see as problematic, but has left them isolated and with diminishing useable space in their homes and increasing risks, including of risk of fire. He is also not dissimilar to many people as they become older, and face the onset of new health conditions and often the comorbidity of issues. Reviewing what went well and where there were gaps in single and multi-agency engagement with Mr. B therefore has the potential to shed light on strengths and where our systems are not reliable in their ability to support people who hoard as they reach older age.

2.3 APPRAISAL SYNOPSIS

- 2.3.1 This review is concerned with a man in his early 80s at a turning point in his life triggered by new health issues. He had an established relationship with the local GP practice, which meant he contacted them readily about his weeping and swollen legs. The initial response was reasonable; Mr. B was seen at the GP surgery and prescribed antibiotics. When it became clear that getting Mr. B to take the antibiotics was not going to be straightforward, the SAR review suggests that the GP practice should have taken a more proactive role in considering how he might effectively be prompted to take them, or what other approaches could

be considered.

- 2.3.2 The GP practice did not seek to ascertain whether there were other barriers to recovery or additional risks of infection posed by his living conditions at home. It does not seem that they were aware that he was almost out of space due to a lifetime of accumulated possessions and this created some unhygienic situations, as well as fire risks. It was a missed opportunity to identify Mr. B's lifetime of hoarding behaviour and implications, and begin to engage with Mr. B about options for minimising the risks this created. **There are no established processes in any agency for working preventatively with older people who have had a lifetime of hoarding. This is discussed further in Finding Three.**
- 2.3.3 Mr. B's first hospital admission occurred two days after last being seen at the GP surgery. This was triggered by Mr B's family members who were really concerned because Mr B was rambling and confused and this was out of the ordinary. The ambulance service were therefore first to ascertain the state of Mr. B's home conditions and identify hoarding behaviour. They correctly ascertained the risks and made an appropriate referral about their safeguarding concerns.
- 2.3.4 Within the hospital there was a swift and effective response to the acute presenting symptoms, that addressed both the infection of his legs and Mr. B's diabetes.
- 2.3.5 The SAR review also identified lots of good practice in responses in relation to hospital discharge planning. It was correct that he was offered support through the Reablement team, which he declined. Practitioners were very attentive to Mr B's capacity in relation to the decision to return home. It was actively discussed by OT and there were three different attempts by people in the SW team.
- 2.3.6 The assessment of Mr B having capacity as a time/place specific assessment was correct. Mental capacity assessments are not able to address transferability to his everyday life at home, when he would not have the three-meals-a-day, the bed to sleep in and the clean environment that he had in the hospital. In this context where he had capacity to decline support on leaving hospital, it was therefore good practice that the hospital social work team had conversations aimed at supporting Mr B to talk about his hoarding, understand the risks, and things he needed to do to mitigate them. Social work staff also provided him with contacts to use if he changed his mind e.g. the Older People's adult social care team.
- 2.3.7 The SAR Review has identified two gaps in responses. The first relates to the interface between the hospital and community based health services. Given the state of Mr B's home, and his reluctance to take medication routinely, specifically antibiotics, and the broad acceptance that the treatment plan was unrealistic, we would have expected engagement with the GP at this stage, and with community nursing, in order to try to provide support following discharge. Without this, Mr. B was left at risk of his leg infection not clearing up fully and indeed, many professionals expected a repeat admission and anticipated that Mr. B would perhaps be more open to accepting support the second time round. **The lack of established systems for following up with community health teams on high risk discharges from hospital is presented in Finding Four.**
- 2.3.8 The second gap in responses to Mr. B on his first hospital admission relates to a

lack of sign posting or referral to support specifically related to hoarding behaviour. **New hoarding guidance has recently been developed by partners locally. The outstanding gaps in helping professionals practically to know what to do, are discussed in Finding Two.**

- 2.3.9 The SAR review has assessed very positively the hospital social work team's responses to the on-going concerns expressed by Mr. B's wife and adult-children both while he was still in hospital and after he was discharged. They did not dismiss what they were saying because they were effectively refuting professionals' decision making about Mr. B's discharge. They were responsive to their concerns and made a referral to PLS for an assessment of potential mental health issues, and later worked sensitively with them to explain what legally could and could not be done within the Mental Capacity Act, Mental Health Act and Article 8 of the Human Rights Act. This was both compassionate and had pragmatic value as they remained the only people in Mr. B's life, and therefore an important source of potential care and support.
- 2.3.10 Unfortunately, however, the concerns raised by Mr. B's family members still did not prompt engagement by the Hospital Social Work team with the GP to request support, for example, via community nursing. Nor did the GP practice initiate involvement in response to a call from Mr. B's adult-child after he was discharged from hospital. The GP Practice appear to have assumed that the fact that the Hospital Social Work team were seeing him, meant there was no role for them. The SAR Review identified this was another missed opportunity for community health services to become involved, via the GP practice.
- 2.3.11 Two weeks after Mr. B's first discharge from hospital, he was readmitted for the same presentational issues, after being found slumped on a bench some miles from home. Again, the ambulance service made an appropriate safeguarding referral, reflecting confidence and familiarity of ambulance staff with when and how to pass on safeguarding concerns. The Hospital Social Work Team took good advantage of the opportunity to engage with Mr. B that this second hospital admission created. They actively sought to persuade Mr. B to consent to being referred to the Reablement team for support post-discharge and were successful. The SAR Review endorse the assessment made at the time, that the priority was 'getting over the threshold' in order to be able to start to build relationships with Mr. B that could open the possibility of providing support in a way that was acceptable to him.
- 2.3.12 The opportunity for input from the Community Mental Health Team (CMHT) Older People's team at this point was lost due to two administrative errors. The Borough Social Work team made a referral made to CMHT Older People's team. The Referral was triaged and accidentally sent to Working Age team. At the time both teams shared a single triage email, making such an error more likely. The error was later spotted and a decision made to re-send to the Older People's team but was the referral was never actually sent. There was no system for tracking referrals at the time, so it was chance that the omission was noticed. The reviewers were advised that an internal tracking system is currently being developed. **The SAR Review has not explored the systems issue further, therefore it does not feature as a systems finding in the body of the report. We draw it to the attention of the SAB in order that assurance can**

nonetheless be sought.

- 2.3.13 The good response by practitioners to the on-going concerns of Mr. B's adult daughter continued at this stage of his second admission to hospital, from Environmental Health and the Fire Service. Environmental Health was prompt and professional in response to the daughter. It was good practice to engage the Fire Service to do a joint visit. They were clear about their role and remit, and what they could not do i.e. clearing the house. They showed awareness of good practice in relation to hoarding, offering to share contacts who could do clearances sensitively working with the person concerned and their family.
- 2.3.14 The delivery of reablement support, the SAR review commends as exceptional. Carers had clear strategies to achieve their aims and establish a rapport with Mr B. They went above and beyond, respecting his particular requirements (calling at set time before a visit), tolerating situations of risk (Mr B locking the front door behind them) and discomfort (sitting on boxes, in a cramped bedroom with the door shut). They were respectful, responsive and flexible, demonstrating a lot of give and take with Mr B e.g. going to alternating days when Mr B said it was too intrusive, as a means of being able to continue the role. The team of carers and managers appeared to support each other well in the over-all task, sharing insights about what worked etc, recognising the easy relationship between Mr B and one of the male carers in particular.
- 2.3.15 Through the carers' relationships they got a sense of his daily patterns e.g. his breakfast routine, including hot drink and leaving washing up to soak; going to his local supermarket and then to the river. They would assess risk in astute ways, so be able to gauge for e.g. if he had been out for long and so potentially be missing. They used their knowledge and relationship with Mr. B to good effect. They were able to influence him e.g. agreeing to a key safe. They engaged with other agencies appropriately and enabled other professionals to engage with him. **The conditions that support such tenacious, flexible, person-centred work by the Reablement team are analysed in Finding One.**
- 2.3.16 Approximately two months after Mr. B's second discharge from hospital, concerns about him increased again. The SAR review note the proactive response by Mr. B's Reablement carers and prompt response by emergency services to the first concerns raised by the Reablement carers. The carers had spoken to him in the morning (14 July) and he had been hallucinating and then they were unable to contact him. They called adult social care initially and were told to call 111. An ambulance was then dispatched due to the safeguarding concern. The ambulance staff could not gain entry so requested police assistance. A neighbour gave the ambulance staff the number of Mr. B's wife, who arrived before the police did and gave access to the house.
- 2.3.17 The Ambulance service assessed the state of the property and correctly judged that a safeguarding referral was needed. They made a detailed referral to Adult Social Care and copied the GP. This was appropriate and good practice. It gave a clear description of the lack of space and some unhygienic aspects in the house due to the accumulation of possessions. They used the clutter rating scale, and logged a high score of eight. They also identified correctly that Mr. B seemed to be sleeping only on a chair, that the gas had been disconnected, there were very few lights working and the fridge was broken. Later Mr. B

himself arrived back and the ambulance seem to have advised for a GP review to be arranged.

- 2.3.18 This incident appears to mark a significant deterioration in Mr. B's condition. However, the documentation across involved agencies has not allowed us to understand with certainty the detail of his hallucinations during this episode or track with confidence the chronology of any subsequent periods involving confusion and hallucinations. This suggests that there was not the detailed attention to this aspect of Mr. B's presentation, that the SAR review suggests would have been appropriate, given his two prior hospital admissions. If he had been successfully treated, why were further bouts of confusion occurring and how might they best be remedied? **The limited focus on how best to address queried delirium in people in the community, compared to acute settings, is addressed in Finding Five.**
- 2.3.19 The GP practice was very responsive in sending out the Urgent Care Practitioner (paramedic) attached to the practice. The Urgent Care Practitioner persisted in efforts to get to see Mr. B, finally succeeding with the intervention of the Reablement carers in the third attempt in two days. Again, documentation has not allowed us to fully understand the extent to which medical tests were completed, or what if any medication was given. Input from the Reablement team at the workshop run as part of this SAR indicated that Mr. B only agreed to have his blood pressure checked but not to give a sample and that antibiotics were left for him to take, but that they saw subsequently that he did not take them. The SAR review consider that at this point consideration should have been given to Mr. B's fluctuating capacity to understand the risks of not taking the antibiotics. Other options for testing and treatment needed to be considered, particularly given the risks associated with both his home conditions and his routine of walking by the river. We understand that the intention of the GP practice was to discuss Mr. B at their Multi-disciplinary Meeting (MDT) however the practice has not been able to find any further notes so it is unclear if this ever happened or what the outcome was.
- 2.3.20 There was good communication between the Urgent Care Practitioner from the GP Practice and the Council's Adult Social Care Older People's Team, and between both and the Reablement carers. Adult Social Care agreed to waive fees in order that the reablement care continued due to identified risks of self-neglect and Mr B not recognising the risks to himself. As with the GP practice response, the SAR Review consider that the significance of Mr. B's bouts of confusion and hallucinations were not given adequate attention as creating new and additional safeguarding concerns. We have questioned whether something more urgent was needed at this stage. There was a reliance on the Reablement carers to continue to monitor Mr. B's situation, when more of a proactive multi-agency response needed to be mobilised. **The limited focus on how best to address queried delirium in people in the community, compared to acute settings, is addressed in Finding Five.**
- 2.3.21 The Reablement carers made an astute identification of the urgency of the situation on the 1st September, when they did not find Mr. B at home, and saw that the alcove in which is sleeping chair was, had collapsed. Their good relationship with Mr. B meant they understood the significance of this for him. Their level of concerns warranted an immediate reporting to the police that he

was missing. However, they had been informed previously that this could only be done after 24 hours.

2.3.22 On the same day he was reported missing, a passer-by saw Mr B on the river embankment near his home and walking into the local river and not resurfacing, and called the police. Very sadly Mr B's body was retrieved from the water and he was pronounced dead at the scene.

2.3.23 The family described the family liaison by police as sympathetic and kind, and reported Mr. B's wife's words accurately. The experience and expertise of the officer who was from the Serious Crime and Complex Investigations team, was evident. It was a very unfortunate error led to a call to the family from an organisation offering bereavement support following suicide of a loved one. The family found this insensitive and distressing.

3 Systems Findings

3.1 INTRODUCTION

- 3.1.1 At the start of the SAR process, the independent reviewers and review team identified three organisational research questions that the case of Mr. B had potential to throw light on. They were confirmed as areas that would not duplicate learning generated elsewhere. They were identified based on what was then known about the case. The stage of the Learning Together SAR process where we move from the case specific analysis to identify generalizable learning, is also the stage where we reflect back on the extent to which our initial assumptions were correct about the organisational areas that this case could shed light.
- 3.1.2 Below we link the original research questions with the systems findings we have identified. What can we learn from Mr B's case about factors in Bedford's adult safeguarding system that help or hinder in
- 1. Picking up changes and/ or deterioration, and the coordination that enables change to be identified and understood (Finding Five)
 - 2. Assessing capacity and working with 'unwise decisions' (Finding One, Finding Two, Finding Three, Finding Four)
 - 3. Establishing who family carers are and mutual expectations about their roles (none)
- 3.1.3 Through the course of the review process, the question of supports to working with family carers emerged as less relevant than the other two research questions. This SAR has therefore not produced generalizable, systems learning in relation to the third original research question.

3.2 FINDINGS OVERVIEW

- 3.2.1 The Review Team has prioritised five findings for the SAB to consider. These are:

	Finding
1	<p>Finding One</p> <p>The commissioning, contracting and culture around reablement services in Bedford create conditions that allow social workers and providers to collectively assess and understand the risks associated with extreme self-neglect in a person-centred way, with the result that they can agree on when they have to be exceptionally flexible in order to engage a group of older people who would otherwise refuse help.</p>
2	<p>Finding Two</p> <p>Local draft guidance for professionals working with adults who have a hoarding disorder is not yet focused enough on practicalities, leaving practitioners without</p>

	adequate clarity about what they need to do and therefore increasing the likelihood that the person concerned gets help when they need it.
3	<p>Finding Three</p> <p>There are currently no arrangements to anticipate the onset of new health conditions or life events for the ageing cohort of people who hoard in Bedford. This leaves vital relationships to be established only at times of crisis, reducing the chances of achieving effective personalised plans to make help and support feasible.</p>
4	<p>Finding Four</p> <p>Mental Capacity assessments are rightly time and decision-specific but there is currently not an established routine of linking with community health providers, to follow up on discharges that are high risk because of the likelihood that the assessment will not hold true in the person's home context.</p>
5	<p>Finding Five</p> <p>The hospital has well-established mechanisms for assessing delirium, but there is a lack of clarity for dealing with delirium in community settings, meaning that someone with delirium is more likely to be assumed to have capacity when in fact they don't, leaving them at risk.</p>

3.3 FINDING 1

3.3.1 The commissioning, contracting and culture around Reablement services in Bedford create conditions that allow social workers and providers to collectively assess and understand the risks associated with extreme self-neglect in a person-centred way, with the result that they can agree on when they have to be exceptionally flexible in order to engage a group of older people who would otherwise refuse help.

3.4 SAR LIBRARY CODING:

3.4.1 This coding helps to specify with more precision the exact nature and relevance of the finding.

Which group of people or situation is this finding relevant to?	Which profession(s) or agencies is the finding relevant to?	Does the finding relate to a particular aspect or type of work within the care and support system	What type of systems issue is it: what kind of thing needs to change?

Not specific	Reablement carers	Reablement	Management system
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3.5 INTRODUCTION

- 3.5.1 Reablement, which is generally provided in the person's own home or care home, is a goal-focused intervention that involves intensive, time-limited assessment and therapeutic work over a period of up to six weeks (but possibly for a shorter period). It involves a process of identifying a person's own strengths and abilities by focusing on what they can safely do instead of what they cannot do anymore.
- 3.5.2 Since 2010 the UK Government has substantially invested in reablement services through NHS funding. It is now set within the context of the Government's broad prevention agenda, which aims to promote wellbeing and help reduce unnecessary hospital admissions, re-admissions and delayed discharges.
- 3.5.3 In England, reablement is seen as a core element of intermediate care that:
- promotes faster recovery from illness
 - prevents unnecessary acute hospital admissions and premature admissions to long-term care
 - supports timely discharge from hospital
 - maximises independent living and reduces or eliminates the need for an ongoing care package.
- 3.5.4 From this information, meaningful functional goals and outcomes are developed with the individual, to promote wellbeing, autonomy, independence and choice. It aims to 'enable people to be and to do what they have reason to value'.
- 3.5.5 One of the key principles of reablement is to support people who are at risk of needing social care or an increased intensity of care to regain functioning, maintain life skills, rebuild their confidence and promote wellbeing.
- 3.5.6 Broadly there are two models of delivery.
- 3.5.7 Intake and assessment services tend to operate a 'de-selective' model, where all those referred for home care undergo reablement unless it is agreed they will not benefit. For example, if someone has end of life care needs, they will be de-selected.
- 3.5.8 In comparison, hospital discharge services usually operate on a more selective basis. They support only those people who are judged likely to benefit from reablement. For example, discharge from hospital of someone who lacks confidence in their abilities following a fall which resulted in injury.
- 3.5.9 In recent years some of the hospital discharge services have broadened their role and evolved into a 'de-selective' model – and, similarly, some intake and assessment services have become more selective (perhaps due to financial pressures).
- 3.5.10 For more information see <https://www.scie.org.uk/reablement/what->

3.6 HOW DID THE FINDING MANIFEST IN THIS CASE?

- 3.6.1 Not all providers would have delivered care to Mr B as a risk assessment done without an understanding of him, could 'on paper' have resulted in a decision that it was too risky to go into his home.
- 3.6.2 In the appraisal synopsis the delivery of reablement support was commended as exceptional. Carers had clear strategies to achieve their aims and establish a rapport with Mr B. They went above and beyond, respecting his particular requirements (calling a set time before a visit), tolerating situations of risk (Mr B locking the front door behind them) and discomfort (sitting on boxes, in a cramped bedroom with the door shut). They were respectful, responsive and flexible, demonstrating a lot of give and take with Mr B e.g. going to alternating days when Mr B said it was too intrusive, as a means of being able to continue the role. The team of carers and managers appeared to support each other well in the over-all task, sharing insights about what worked etc, recognising the easy relationship between Mr B and one of the male carers in particular.
- 3.6.3 Through the carers' relationships they got a sense of his daily patterns e.g. his breakfast routine, including hot drink and leaving washing up to soak; going to his local supermarket and then to the river. They would assess risk in astute ways, so be able to gauge for e.g. if he had been out for long and so potentially be missing. They used their knowledge and relationship with Mr. B to good effect. They were able to influence him e.g. agreeing to a key safe. They engaged with other agencies appropriately and enabled other professionals to engage with him.

3.7 HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

- 3.7.1 As part of the review process, we explored the extent to which the tenacity and flexibility from providers in delivering a service is usual. The care provider agency explained that the terms on which they are commissioned enable the culture and practices of the provider as standard. They work on a task and goal basis, rather than allocating a slot of time for a visit, as is more commonly the case with care agencies who are not working on the reablement contract. So Mr B was not alone in receiving an amount of time judged sufficient to build up and maintain a relationship with him in the context of his reluctance to receive any help or support. Nor was his case unique in having carers who were expert and empowered to be responsive to his preferences as a means of providing the maximum amount of help and support possible with consent.

3.8 HOW WIDESPREAD IS THIS SYSTEMS FINDING?

- 3.8.1 We use this section to lay out evidence we have gathered about how many facilities are actually or potentially affected by this finding.
- 3.8.2 Discussions at a review team meeting suggested that this conducive set up to achieving personalized provision tends to be restricted to reablement services.

Such conditions appear to be anathema to other forms of home care provision.

3.9 HOW PREVALENT

- 3.9.1 We use this section to lay out how many cases are actually or potentially affected by the systemic issues highlighted in this finding.
- 3.9.2 All the professionals who contributed to the review spoke of the time needed to build a rapport with adults at risk who are reluctant to accept services. As well as adults at risk of self-neglect, who may also hoard, people with dementia can also take time to engage and accept any form of help, so this increases the size of the population who could benefit from the kind of flexible, tenacious service that the Reablement teams are enabled to provide. We have not been able to put figures to ascertain the size of this cohort.

3.10 FINDING 1 SUMMARY AND QUESTIONS FOR THE SAB & PARTNERS

3.10.1 The commissioning, contracting and culture around Reablement services in Bedford create conditions that allow social workers and providers to collectively assess and understand the risks associated with extreme self-neglect in a person-centred way, with the result that they can agree on when they have to be exceptionally flexible in order to engage a group of older people who would otherwise refuse help.

3.11 SUMMARY

3.11.1 Reablement is a strengths-based, person-centred approach that promotes and maximises independence and wellbeing. It aims to ensure positive change using user-defined goals and is designed to enable people to gain, or regain, their confidence, ability, and necessary skills to live as independently as possible, especially after an illness, deterioration in health or injury. Currently, reablement is available via a hospital discharge model, leaving other cohorts of people who would benefit from the flexible, personalized ethos of engagement unable to easily benefit from this type of service.

3.12 QUESTIONS FOR THE SAB TO CONSIDER:

- 3.12.1 Has there been any discussion at or enabled by the SAB, of the relevance of Reablement to the embedding of Making Safeguarding Personal across Bedford?
- 3.12.2 Is the Board aware, or would the Board be made aware, of any threats to the hospital's commissioning premise of Reablement services?
- 3.12.3 How might the SAB support consideration of the potential transferability of learning about enabling conditions of the personalised approach of the Reablement Team, to service development more generally?
- 3.12.4 Has there been a cost benefit analysis locally of using a permanent

3.13 FINDING TWO

3.13.1 Local draft guidance for professionals working with adults who have a hoarding disorder is not yet focused enough on practicalities, leaving practitioners without adequate clarity about what they need to do and therefore increasing the likelihood that the person concerned gets help when they need it.

3.14 SAR LIBRARY CODING:

3.14.1 This coding helps to specify with more precision the exact nature and relevance of the finding.

Which group of people or situation is this finding relevant to?	Which profession(s) or agencies is the finding relevant to?	Does the finding relate to a particular aspect or type of work within the care and support system	What type of systems issue is it: what kind of thing needs to change?
People with hoarding behaviour	Not specific	Not specific	Tools

3.15 INTRODUCTION

3.15.1 The NHS website summarises the difficulties that explain why the risks associated with hoarding can bring it into adult safeguarding:

- Hoarding disorders are challenging to treat because many people who hoard frequently do not see it as a problem, or have little awareness of how it's affecting their life or the lives of others.
- Many do realise they have a problem but are reluctant to seek help because they feel extremely ashamed, humiliated or guilty about it.
- It's really important to encourage a person who is hoarding to seek help, as their difficulties discarding objects can not only cause loneliness and mental health problems but also pose a health and safety risk.

3.15.2 The Clutter Image Rating (CIR) scale was developed in recognition that people's reports of clutter is subjective. It is a visual aid using sets of 9 photos to help establish where on the 1-9 scale someone's hoarding is.

3.15.3 The NHS summary also illustrates how hoarding links to personalisation. Working sensitively and at their own pace with someone who hoards has been shown to be effective. One of the Review Team members in Bedford confirmed that to 'just go in and clear their house' can be 'catastrophic' for someone with

hoarding disorder, however well-intentioned.

3.15.4 Agencies that can or do offer help include:

- Bedfordshire Fire and Rescue Services offer a home fire safety check as one way of helping with hoarding, and have a 'help with hoarding' section on their website, which lists the risks associated with hoarding.
- The local authority environmental health service can advise as well and carry out joint visits with their Fire Service colleagues. Private companies offer what is said to be a personalised service to help
- BPHA, a local housing association, runs hoarders' groups for its tenants. This approach was shortlisted in the **Outstanding Innovation of the Year category in the UK Housing Awards 2017**. It also created a support group for hoarders, which helps tenants to try to improve their situation, lower the risk to other tenants and retain their tenancies. Monthly De-Clutter Group meetings, held in Bedford, are part of the support service.

3.16 HOW DID THE FINDING MANIFEST IN THIS CASE?

3.16.1 A running theme through this case, was the challenge felt by all professionals and his family members alike, about what they were able to do in the face of the obvious risks posed by the state of Mr B's home given the extent of his accumulated possessions. People felt at a loss for what to do. His capacity to make the decision to return home and understand the risks became a barrier to working with him about his hoarding and options to reduce the risks it created. We saw professionals exploring whether the Mental Health Act offered them any leverage, but it did not because there were no other mental health problems. While we have been extremely positive about the engagement by the Reablement carers, they were not required, nor did they claim particular expertise around hoarding. The Fire and Rescue services made safeguarding referrals but were also frustrated that these did not produce any tangible results.

3.13.2

3.17 HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

3.17.1 As part of the review process, we explored the extent to which this level of risk related to hoarding behaviour and professionals being at a loss as to how to deal with it, is usual.

3.17.2 All the professionals in the Review Team described that unresolved risk around hoarding disorder is a perplexing problem. One issue is that there are not consistent pathways agreed between all organisations about how to proceed with hoarding, adding to the feeling of being stuck once options have been exhausted. The Fire and Rescue Service and the Ambulance Service have an agreement about hoarding but this is not mirrored either with other organisations or in an overarching agreement. The General Data Protection Regulation of 2018 has created a perception that sharing information about people who are at risk without their explicit consent, is more difficult than it used to be.

3.17.3 It was described as a difficulty that preoccupies professionals on a regular basis. This was illustrated by the fact that the NHS Clinical Commissioning Group and

the Fire Service are working to establish a hoarding group.

3.17.4 It also lies behind SAB action to develop multi-agency guidance. However, during the time that the SAR review was taking place, the guidance was updated and approached finalization. The process highlighted that the updated Guidance will need to address the 'so what?' question. There was marked consistency in people feeling they needed more clarity about where to signpost individuals to e.g. if there are charities working with people who hoard, and established pathways into and out of relevant organisations.

3.18 HOW WIDESPREAD IS THIS SYSTEMS FINDING?

3.18.1 Within the constraints of the review we ascertained that the lack of practicality in guidance available about responding to people who hoard was relevant across the whole of Bedfordshire. Anecdotally, there seems variability across regions nationally.

3.19 HOW PREVALENT

3.19.1 We use this section to lay out how many cases are actually or potentially affected by the systemic issues highlighted in this finding,

3.19.2 Identifying how many people are known to hoard is not straightforward, and even then is likely to be an underestimate. Across the county of Bedfordshire, the Bedfordshire Fire and Rescue Service reports that in the last three years a total of 88 adults have hoarding disorder with the breakdown being:

- Bedford Borough – 13
- Central Beds – 35
- Luton – 40

3.19.3 So, it is a small cohort of people we are talking about.

3.20 FINDING TWO SUMMARY AND QUESTIONS FOR THE SAB & PARTNERS

3.20.1 Local draft guidance for professionals working with adults who have a hoarding disorder is not yet focused enough on practicalities, leaving practitioners without adequate clarity about what they need to do and therefore increasing the likelihood that the person concerned gets help when they need it.

3.21 SUMMARY

3.21.1 There are a small but significant number of people known locally to be affected by hoarding. They have recently come up the agenda with the development of multi-agency guidance to support professionals to understand the phenomenon and provide appropriate and timely help. This finding has indicated that the guidance is not yet practical enough, leaving professionals

still at sea as to what they can actually do and lessening the chances of people who hoard being given the help that suits them.

3.22 QUESTIONS FOR THE SAB TO CONSIDER:

3.22.1 Will the SAB be considering the Bedfordshire hoarding guidance before it is finalised?

3.22.2 How will the SAB review the impact of this guidance?

3.22.3 The Joint Strategic Needs Assessment for Bedford is clear on the value of prevention, what does the SAB think of this in relation to hoarding?

3.22.4 How will the SAB know if practitioners feel better supported and/or responses to people who hoard has improved?

3.23 FINDING THREE

3.23.1 **There are currently no arrangements to anticipate the onset of new health conditions or life events for the ageing cohort of people who hoard in Bedford. This leaves vital relationships to be established only at times of crisis, reducing the chances of achieving effective personalised plans to make help and support feasible.**

3.24 SAR LIBRARY CODING:

3.24.1 This coding helps to specify with more precision the exact nature and relevance of the finding.

Which group of people or situation is this finding relevant to?	Which profession(s) or agencies is the finding relevant to?	Does the finding relate to a particular aspect or type of work within the care and support system	What type of systems issue is it: what kind of thing needs to change?
Older people with a lifetime of hoarding behaviour	Not specific	Not specific	Management system

3.25 INTRODUCTION

3.25.1 Finding Two gave a brief introduction hoarding and the risks associated, that

explain why hoarding becomes relevant to adult safeguarding:

- Hoarding disorders are challenging to treat because many people who hoard frequently do not see it as a problem, or have little awareness of how it's affecting their life or the lives of others.
- Many do realise they have a problem but are reluctant to seek help because they feel extremely ashamed, humiliated or guilty about it.
- It's really important to encourage a person who is hoarding to seek help, as their difficulties discarding objects can not only cause loneliness and mental health problems but also pose a health and safety risk.

3.25.2 Reaching older age likewise brings some fairly predictable changes and associated risks. These include developing physical frailty, health problems and co-morbidity of health issues. For older people who hoard, there is the additional risk created by the amount of possessions that they can have been able to accumulate simply by the amount of time that they have had.

3.25.3 Bedford's Joint Strategic Needs Assessment (JSNA) provides a comprehensive picture of what we know about the health and wellbeing of the people living in Bedford Borough. "The best way to add life to years and years to life is to stop people becoming ill in the first place. Prevention is highly cost-effective, although it often requires investment upfront to prevent poor health and wellbeing in the future. As well as the benefits to individuals and families, preventing ill health and improving wellbeing reduces the need for expensive health and social care, and has wider benefits to society".

3.25.4 This is relevant because adults who hoard or neglect themselves are predictably going to reach a point where life events or developing one more additional health condition on top of existing ones, mean that they can no longer cope. Applying prevention principles is not only better for them but cost-effective for the system as a whole.

3.26 HOW DID THE FINDING MANIFEST IN THIS CASE?

3.26.1 Mr. B had had a life-time of hoarding. He had always lived his life the way he wished to, despite exasperating his family and friends at times. The result was that he was isolated in a property he owned, which was increasingly in disrepair, and almost out of space due to accumulated possessions. As he entered his 80s, there was a certain amount of predictability to some kind of new health issues emerging particularly given his diabetes, and progressively failing eye sight. There was a certain amount of predictability too, that the state of his home conditions would make it difficult for him to manage the onset of any new health issues and could put him at considerable and increasing risk in his home and daily routine.

3.26.2 Mr B had a long-standing relationship with his local GP practice, as did his family members. However, the SAR review did not identify any work initiated by professionals with Mr B in anticipation of increased risks presented by his hoarding, in the context of his increasing age, frailty and/or new health conditions. This meant that there were no established relationships with between Mr. B and particular practitioners on which to build, at the point when something

really needed to be done, such as clear a single room on the ground floor that he could sleep with his legs raised, and be in a hygienic environment, so as to enable his leg wounds to heal.

3.27 HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

- 3.27.1 When this issue was discussed as part of the SAR Review, input confirmed that there are no preventive measures for people who hoard, whether linked to their reaching older age, mental health or other life events. The concept of prevention was not one associated with people with hoarding behaviours.
- 3.27.2 There is a tension, which the Review Team discussed, around the fact that it is predictable that some adults who self-neglect and hoard, are typically reluctant to accept help. This makes any sort of early intervention difficult – partly because they do not welcome it and partly because when they have mental capacity, there is no remit for services to get involved. Yet it is in precisely these scenarios that relationship-based practice is most needed and effective.
- 3.27.3 Only the Bedfordshire Fire and Rescue Service identified themselves as having some capacity in their system to do longer term engagement with people who self neglect, including people who hoard. To-date this has, understandably, focused predominantly on fire safety.

3.28 HOW WIDESPREAD IS THIS SYSTEMS FINDING?

- 3.28.1 Discussions as part of this review did not surface any examples of areas where there were arrangements for preventative work with older people with a life-time of hoarding, to anticipate the need to make some changes due to the likely onset of new health conditions and frailty.

3.29 HOW PREVALENT

- 3.29.1 We use this section to lay out how many cases are actually or potentially affected by the systemic issues highlighted in this finding,
- 3.29.2 Identifying how many people are known to hoard is not straightforward, and even then is likely to be an underestimate. Across the county of Bedfordshire, the Bedfordshire Fire and Rescue Service reports that in the last three years a total of 88 adults have hoarding disorder with the breakdown being:
- Bedford Borough – 13
 - Central Beds – 35
 - Luton – 40
- 3.29.3 Identifying the numbers of people who hoard who are in their 70s and 80s is even harder. More generally, the Strategic Needs Assessment identifies that an estimated 65,100 people in Bedford Borough are over the age of 50, of whom 31,200 are over 65 and 4,500 are over 85 (ONS 2017). Most notably, the 85+ population is forecast to increase by around 20% by 2025. This will have major implications for health and social care services in the Borough.
- 3.29.4 So, it is a small but often highly vulnerable and isolated cohort of people actually

or potentially affected by this finding.

3.30 FINDING THREE SUMMARY AND QUESTIONS FOR THE SAB & PARTNERS

3.30.1 There are currently no arrangements to anticipate the onset of new health conditions or life events for the ageing cohort of people who hoard in Bedford. This leaves vital relationships to be established only at times of crisis, reducing the chances of achieving effective personalised plans to make help and support feasible.

3.31 SUMMARY

3.31.1 The Joint Strategic Needs Assessment for Bedford is clear on the value of prevention, but this finding highlights a small but important cohort of people for whom there is as yet no prevention agenda: people with a life-time of hoarding as they enter older age. Engaging respectfully with people who hoard and building relationships is an essential foundation for helping them minimize the risks of their hoarding behaviour. If this process only begins at points of crises for older people, it significantly reduces the chances of identifying help that is the person deems acceptable and to which they will consent, and significantly increasing the chances of them being repeatedly admitted to hospital.

3.32 QUESTIONS FOR THE SAB TO CONSIDER:

3.32.1 The Joint Strategic Needs Assessment for Bedford is clear on the value of prevention, what does the SAB think of this in relation to hoarding?

3.32.2 Who would be best placed to consider whether and/or how to develop more of a prevention agenda for people who hoard as they enter older age?

3.32.3 Will the SAB be seeking feedback from the initiative by the NHS Clinical Commissioning Group and Bedfordshire Fire and Rescue Service to set up a hoarding prevention panel to reduce risk and to what end?

3.32.4 Would the SAB be able to identify if this situation had improved? Are any changes to the data reported in required?

3.33 FINDING FOUR

3.33.1 Mental Capacity assessments are rightly time and decision-specific but there is currently not an established routine of linking with community health providers, to follow up on discharges that are high risk because of the likelihood that the assessment will not hold true in the person’s home context.

3.34 SAR LIBRARY CODING:

3.34.1 This coding helps to specify with more precision the exact nature and relevance of the finding.

Which group of people or situation is this finding relevant to?	Which profession(s) or agencies is the finding relevant to?	Does the finding relate to a particular aspect or type of work within the care and support system	What type of systems issue is it: what kind of thing needs to change?
People who hoard	Community health providers	Hospital discharge	Management system issue

3.35 CONTEXT

3.35.1 The Mental Capacity Act 2005 (MCA) and the associated Code of Practice is empowering legislation and had required risk aversion and paternalistic cultures be addressed. It supports the values and practice of personalisation by empowering people to make their own decisions.

3.35.2 The MCA is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over. It covers decisions about day-to-day things like what to wear or what to buy for the weekly shop, or serious life-changing decisions like whether to move into a care home or have major surgery.

3.35.3 The Act supports the values and practice of personalisation by empowering people to make their own decisions. The MCA says that it must be assumed that a person has capacity to make a specific decision unless it is demonstrated that they are unable to do so. A person’s opportunity to make their own decisions should be maximised by giving them all possible support.

3.35.4 Particularly relevant for this case is that someone can lack capacity to make some decisions (for example, to decide on complex financial issues) but still have the capacity to make other decisions (for example, to decide what items to buy at the local shop). Mental capacity assessment is therefore time and decision specific and never transferable. Sometimes it’s incorrectly said that someone ‘has capacity’ or ‘lacks capacity’ as a general view on their abilities. This is not in

line with the MCA. Rightly then, capacity assessments are not transferable. This has particular implications for hospital professionals and families worried about the reliability of discharge plans. As the review team in this case heard, sometimes people are much more confused in hospital and do better once they are back home. For others like Mr B, and as his family pointed out, having meals, taking medication and being in a bed means that professionals see them at their best and know that they are much more at risk in their home context.

3.36 HOW DID THE FINDING MANIFEST IN THIS CASE?

- 3.36.1 Following Mr B's first hospital admission, the SAR review identified lots of good practice in responses in relation to hospital discharge planning. It was correct that he was offered support through the Reablement team, which he declined. Practitioners were very attentive to Mr B's capacity in relation to the decision to return home. It was actively discussed by OT and there were three different attempts by people in the SW team.
- 3.36.2 The assessment of Mr B having capacity as a time/place specific assessment was correct. Mental capacity assessments are not able to address transferability to his everyday life at home, when he would not have the three-meals-a-day, the bed to sleep in and the clean environment that he had in the hospital. In this context where he had capacity to decline support on leaving hospital, it was therefore good practice that the hospital social work team had conversations aimed at supporting Mr B to talk about his hoarding, understand the risks, and things he needed to do to mitigate them. Social work staff also provided him with contacts to use if he changed his mind e.g. the Older People's adult social care team.
- 3.36.3 One of the gaps SAR Review has identified in hospital discharge planning relates to the interface between the hospital and community-based health services. Given the state of Mr B's home, and his reluctance to take medication routinely, specifically antibiotics, and the broad acceptance that the treatment plan was unrealistic, we would have expected engagement with the GP at this stage, and with community nursing, in order to try to provide support following discharge. Without this, Mr. B was left at risk of his leg infection not clearing up fully and indeed, many professionals expected a repeat admission and anticipated that Mr. B would perhaps be more open to accepting support the second time round.
- 3.36.4 Indeed, on his second admission it was noted that "[the] doctors have reviewed [his] leg ulcers and report that these may be a result of poor hygiene and also possibly related to knocking of his shins on items within the home due to excessive clutter...".

3.37 HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

- 3.37.1 When we discussed this issue as part of the SAR review process, there was acknowledgment of the gap as standard. This was contrast, for example, with the routine 72 hour follow-up that takes places after discharge from a Mental Health ward. There is not currently an established way too share concerns with someone else who could recheck the assessment in the different, home

environment

- 3.37.2 The role of the General Practitioner was felt to be crucial and the example was given that in Bedford, a hospital consultant may write to a GP in the case of a high-risk discharge caused by a patient's refusal of care, to highlight that the professionals who have assessed them feel that care is very much needed.
- 3.37.3 Questions were also raised about the role of community nursing services and also that of community matrons. The community nursing service did not appear to have been considered for Mr B but could provide a follow-on service when there are concerns of the sort identified in this Finding. Meanwhile the Community Matron targets adults with complex health needs and again had not, from conversations with hospital professionals, and with the GP, been considered as an option.
- 3.37.4 So it became clear that currently there is not an established routine of linking with community health providers, to follow up on discharges that are high risk because of the likelihood that the assessment will not hold true in the person's home context.

3.38 HOW WIDESPREAD IS THIS SYSTEMS FINDING?

- 3.38.1 The reviewers did not see any evidence to suggest that this finding is not relevant across Bedford Borough and Central Bedfordshire. We did not have the opportunity to explore whether it was a regional or national issue. One example was given of an adjoining local authority area where there is a 'community arm' of the hospital social work service to follow on in situations of comparable risk. This suggests that arrangements do exist in some areas..

3.39 HOW PREVALENT

- 3.39.1 We have not been able to access figures on how many hospital discharges are made where the person had been assessed as having capacity to refuse care but professionals are worried about the transferability of the capacity assessment to the person's home conditions and every-day life.
- 3.39.2 As in Mr. B's case this is likely to affect people whose homes are affected by hoarding. As stated in earlier findings, identifying how many people are known to hoard is not straightforward, and even then is likely to be an underestimate. Across the county of Bedfordshire, the Bedfordshire Fire and Rescue Service reports that in the last three years a total of 88 adults have hoarding disorder with the breakdown being:
- Bedford Borough – 13
 - Central Beds – 35
 - Luton – 40
- 3.39.3 We have not ascertained what portion of these have had hospital admissions.

3.40 FINDING FOUR SUMMARY AND QUESTIONS FOR THE SAB & PARTERS

3.40.1 Mental Capacity assessments are rightly time and decision-specific but there is currently not an established routine of linking with community health providers, to follow up on discharges that are high risk because of the likelihood that the assessment will not hold true in the person's home context.

3.41 SUMMARY

3.41.1 The Mental Capacity Act (2005) is empowering legislation and has required risk aversion and paternalistic cultures be addressed. Competent practice in applying the MCA requires effective balancing of sometimes competing principles in complex situations. Yet this finding has highlighted a gap in inter-agency working between hospital and social work staff, and their community health colleagues in relation to the transferability of a patients' mental capacity assessments from hospital to their home environments, that would help address more complex situations. Without established mechanisms and routines, failed hospital discharges are more likely, with the associated risks for patients, expense for services and distress for families.

3.42 QUESTIONS FOR THE SAB TO CONSIDER:

3.42.1 Does the SAB consider that this is enough of a safeguarding issue to merit follow up?

3.42.2 What data does the SAB hold that could help with exploration of this issue?

3.42.3 How can GP practices best be engaged in discussion of possible resolutions to this issue?

3.42.4 Would the SAB be able to tell if the situation had improved?

3.43 FINDING FIVE

3.43.1 The hospital has well-established mechanisms for assessing delirium, but there is a lack of clarity for dealing with delirium in community settings, meaning that someone with delirium could be assumed to have capacity when in fact they don't, leaving them at risk.

3.44 SAR LIBRARY CODING:

3.44.1 This coding helps to specify with more precision the exact nature and relevance

of the finding.

Which group of people or situation is this finding relevant to?	Which profession(s) or agencies is the finding relevant to?	Does the finding relate to a particular aspect or type of work within the care and support system	What type of systems issue is it: what kind of thing needs to change?
Not specific	All community based services	Assessing and responding to confusion and hallucinations, where there is a query of delirium	Management system

3.45 INTRODUCTION

3.45.1 Delirium – the onset of sudden confusion – is of significant concern to professionals working with older adults because it can be caused by a serious condition requiring urgent treatment. NHS Choices website gives the following possible causes: an infection (urinary tract infections are a common cause of delirium in older people or people with dementia; a stroke or mini stroke; low blood sugar in people with diabetes; a head injury. The NHS advice is to seek medical help immediately. The effect on an older person is distressing and puts them at considerable risk - If a person is confused, they may:

- not be able to think or speak clearly or quickly
- not know where they are (feel disorientated)
- struggle to pay attention or remember things
- see or hear things that aren't there (hallucinations)

3.45.2 In hospital settings (acute trusts) delirium can be managed effectively because the patient is present and there are diagnostic tests and treatments. In the community the risks are far higher for all the reasons in the bullet points above.

3.45.3 'Community' includes the following services that support older people in their own homes and who have a role in diagnosing and treating delirium:

- The GP and other practice staff such as the paramedic in Mr B's case
- Nursing services – the more general community service as well as Community Matrons who deal specifically with adults who have multiple complex health conditions
- The mental health trust who can support the efforts of other professionals by assessing using the Mental Health Act in some cases
- The police who encounter confused adults and need to know how to respond
- Ambulatory care and other clinics that bridge hospital and community services also have a role in delivering treatment

- Social workers can be involved on a case by case basis too
- As seen in Mr B's case, home care workers such as the Reablement Team, are often crucial identifying delirium and asking for appropriate assessment

3.46 HOW DID THE FINDING MANIFEST IN THIS CASE?

- 3.46.1 Mr B himself reported hallucinations in July 2018. This resulted in his friend and then later his reablement service carer calling NHS 111 who advised contacting his GP practice. As we described in the appraisal of practice synopsis, this incident appears to mark a significant deterioration in Mr. B's condition. However, the documentation across involved agencies has not allowed us to understand with certainty the detail of his hallucinations during this episode or track with confidence the chronology of any subsequent periods involving confusion and hallucinations. This suggests that there was not the detailed attention to this aspect of Mr. B's presentation, that the SAR review suggests would have been appropriate, given his two prior hospital admissions. If he had been successfully treated, why were further bouts of confusion occurring and how might they best be remedied?
- 3.46.2 The GP practice was very responsive in sending out the Urgent Care Practitioner (paramedic) attached to the practice. The Urgent Care Practitioner persisted in efforts to get to see Mr. B, finally succeeding with the intervention of the Reablement carers in the third attempt in two days. Again, documentation has not allowed us to fully understand the extent to which medical tests were completed, or what if any medication was given. Input from the Reablement Carers at the workshop run as part of this SAR indicated that Mr. B only agreed to have his blood pressure checked but not to give a sample and that antibiotics were left for him to take, but that they saw subsequently that he did not take them. The SAR review consider that at this point consideration should have been given to Mr. B's fluctuating capacity to understand the risks of not taking the antibiotics. Other options for testing and treatment needed to be considered, particularly given the risks associated with both his home conditions and his routine of walking by the river. Review team members from the mental health trust have described, as part of this SAR review process, some of the actions they can take to help colleagues from other services to assess delirium, for example. The starting point in the mental health trust is that delirium in the community is particularly tricky precisely because it does have implications for capacity.
- 3.46.3 We understand that the intention of the GP practice was to discuss Mr. B at their Multi-disciplinary Meeting (MDT) however the practice has not been able to find any further notes so it is unclear if this ever happened or what the outcome was.
- 3.46.4 There was good communication between the Urgent Care Practitioner from the GP Practice and the Council's Adult Social Care Older People's Team, and between both and the Reablement carers. Adult Social Care agreed to waive fees in order that the Reablement Care continued due to identified risks of self-neglect and Mr B not recognising the risks to himself. As with the GP practice response, the SAR Review consider that the significance of Mr. B's bouts of confusion and hallucinations were not given adequate attention as creating new and additional safeguarding concerns. We have questioned whether something

more urgent was needed at this stage. There was a reliance on the Reablement Carers to continue to monitor Mr. B's situation, when more of a proactive multi-agency response needed to be mobilised.

3.47 HOW DO WE KNOW IT'S UNDERLYING NOT A ONE-OFF?

3.47.1 When we discussed this issue further as part of the SAR process, input from the review team contrast the situation with the work of the hospital. We were told of extensive work that is being focused on delirium in acute settings, including this issue of capacity and its fluctuation in the case of delirium. In the hospital the risk of delirium and not taking medication, has prompted thinking about norms and the hospital response has been by beginning to ask for advance decisions whereby practitioners ask when the person is well what they want to happen if their capacity fluctuates. The hospital is audited annually in order that national data can be produced can shared.

3.47.2 Participants highlighted the contrast of this picture in acute settings with that of approaches to delirium in community settings across Bedford. There is not the equivalent clarity around the need to, or processes for following up and assessing capacity, fluctuating or affected by the delirium, and associated risks when someone is at home and therefore at greater risk. It is not routine to draw on the help of other services, such as the Mental Health Trust other than in extreme circumstances. The Approved Mental Health Practitioner service has been known to apply for warrants to take people with delirium to places of safety, even if the person is judged to have capacity, because the risk of delirium in some cases is so high. This service has received GP requests in the past for exactly this assessment.

3.48 HOW WIDESPREAD IS THIS SYSTEMS FINDING?

3.48.1 We use this section to capture how geographically far the systems issue identified is spread. We have had limited capacity to explore this but input from the Review Team suggested that it is likely to be both a borough wide issue and also hold true at regional, and perhaps national levels.

3.49 HOW PREVALENT

3.49.1 We use this section to capture details about how many people are actually or potentially affected by this finding. Within the timescales of this review, we have not ascertained the number of people in community settings who experience confusion and/or hallucinations where delirium was a potential cause.

3.50 FINDING FIVE SUMMARY AND QUESTIONS FOR THE SAB & PARTNERS

3.50.1 The hospital has well-established mechanisms for assessing delirium, but there is a lack of clarity for dealing with delirium in community settings, meaning that someone with delirium could be assumed to have capacity when in fact they don't, leaving them at risk.

3.51 SUMMARY

3.51.1 The assessment of whether or not a person has capacity to decide on whether they wish to complying with treatment health professionals are recommended and the risks involved, has potentially significant consequences for their health and their safety. If a person has delirium, the risk of not taking medication are high and therefore fluctuating capacity has to be considered. Yet this finding highlights that while there is concerted work being focused on this area in acute settings, there is nothing like the same attention being given to the issue in community settings. This leaves norms of starting with an assumption that someone has capacity unchallenged, in situations where there have been any bouts of confusion or hallucination and actually, the fact of delirium may mean they do not have capacity. This increases the chances that people will not get the medication they need to treat the delirium, and leave them unprotected from the associated risks. The starting point in the mental health trust is that delirium in the community is particularly tricky precisely because it does have implications for capacity, but this is not yet a shared assumption across community partners.

3.52 QUESTIONS FOR THE SAB TO CONSIDER:

3.52.1 Does the Board need to know more about how big a problem dealing with query delirium in community settings is?

3.52.2 Who is best placed to address the lack of clarity about how best to deal with query delerium in community settings?

3.52.3 How would the SAB know if the situation had improved?

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